Beat
Eating disorders

HELPING A LOVED ONE RECOVER FROM AN EATING DISORDER:

A guide for families and carers

HELPING YOU HELP YOUR LOVED ONE RECOVER FROM AN EATING DISORDER

Having a loved one receive a diagnosis of an eating disorder often feels confusing, overwhelming and scary. Frequently family, friends and partners report having lots of questions about the diagnosis and what they can do to support their loved one. This pack aims to answer some of these questions, and to provide you with helpful information and resources. There is also a glossary of terms you might commonly hear, which you may want to refer to as you go through the pack.

While there is no quick fix for an eating disorder, recovery is possible. People can and do get better with the right help and support. You can play an essential role in your loved one's recovery, with research suggesting that people have a better chance of recovery with the help of a skilled and knowledgeable carer.

"My message to all carers is please do not blame yourself. You did not cause your loved one's illness but you are their best resource for supporting them to get better. Time spent feeling guilty and blaming yourself is just using precious emotional energy that you so desperately need for yourself, your loved one and the rest of your family during this difficult time. You are doing an amazing job in educating yourself so you can provide the best possible support for your loved one. Try and keep positive and look out for those small victories or improvements along the way. Always be kind to yourself and seek help from others if you need it."

HOW TO USE THE PACK

AS A CLINICIAN

For adults who have been diagnosed with an eating disorder, please remove section 6a Evidence-Based Outpatient Treatments: Children and Young People

AS A CARER

This pack is designed to answer some of the questions you may have about eating disorders, treatment for your loved one, and how to look after yourself. It is for anyone who is supporting someone who has been diagnosed with an eating disorder, whether you are a partner, friend, parent, sibling, or another family member.

Having lots of information can be helpful for some people, while for others this may be overwhelming, so go through the pack at a pace that feels manageable for you.

"I was in your position just over four years ago. It is a very daunting and lonely time to begin with, but it does get better. I would recommend reading up about eating disorders and taking as much advise from professionals as you can. The journey to recovery is not easy but it is possible with a LOT of patience. Your loved one may be angry with you in the beginning but eventually they will thank you for your love and support. You must also take time to care for yourself as this will test you big time, but the rewards are so obviously worth it."

Summary:

- Eating disorders are serious mental illnesses that involve someone having difficulties with their eating behaviours, thoughts and emotions.
- The person may eat too little, eat too much in one go and/or try to get rid of food that they have eaten.
- Despite what it looks like, eating disorders are not really about food. Instead, they're more about how someone is thinking and feeling.
- This section includes information about the five most common types of eating disorder: anorexia nervosa, bulimia nervosa, binge eating disorder, other specified feeding or eating disorder (OSFED) and avoidant/restrictive food intake disorder (ARFID).
- Each eating disorder can cause serious problems, but these normally improve with the right help and treatment.
- People with eating disorders can and do get better with the right help and support.

What are Eating Disorders?

Eating disorders are serious mental illnesses that involve severe disturbances to someone's eating behaviours, thoughts and emotions. These behaviours may involve the person restricting their food intake, eating large quantities of food at once with a sense of having lost control ('bingeing'), compensating for food eaten through purging (trying to get rid of the food), fasting or excessive exercise, or a combination of these behaviours. It is important to remember that, despite how it may seem, eating disorders are not about food. Instead, eating disorders often serve a function in someone's life. For example, they might be a coping mechanism, a way for the person to communicate a certain emotion, or a means of helping the person feel in control. Eating disorders can be difficult to identify and often those who have them can appear healthy despite being unwell.

In order to aid treatment, eating disorders are often split into diagnostic categories depending on behaviours and symptoms. It is common for people to move between diagnoses, since there is a lot of overlap between them. Therefore, while we suggest focusing on the sheets relevant to your loved one's current diagnosis, this pack contains information about other eating disorders as well.

"The eating disorder allowed me to feel like I had control over something and provided an escape from the pressures of reality. I now see that the eating disorder actually had control over me, and I was a slave to what it told me to do."

"It is good to remember that so many people with eating disorders go on to recover and have amazing lives. Never give up – recovery is possible."

Anorexia Nervosa

Anorexia nervosa involves persistent restriction of food intake, which is likely to lead to someone becoming significantly underweight. Someone diagnosed with anorexia nervosa is likely to have an intense fear of gaining weight or of becoming "fat", and have a distorted view of themselves. As well as restricting, the person may also binge eat and/or purge.

People with anorexia nervosa may also show obsessive behaviours such as compulsive exercising, counting calories, and food rituals like cutting their food into small pieces. As well as limiting the amount of food they eat, they also tend to restrict the types of foods they can eat. People with anorexia nervosa are often preoccupied with thoughts about food, their weight and their shape. They may wear baggy clothes as a way to hide their weight loss or prevent others from seeing their body, or due to difficult thoughts around wearing certain clothes, including the feel of certain clothing on the body being hard to tolerate.

Physical consequences

Starvation affects all the body's organs, including the brain and muscle tissue. Therefore, as well as being underweight, people with anorexia nervosa often experience other physical signs of starvation. These may include poor circulation, feeling cold, lanugo (fine hair on the body and face), dizziness, tiredness, low blood-pressure, and low hormone levels. which can lead to amenorrhea (the absence of periods) in females and reduced testes size in males, reduced libido (sexual drive), fertility problems and osteoporosis (weakened bones). People with anorexia nervosa are also at risk of problems with their heart, kidneys and bowels. They may also have a weakened immune system. Anorexia nervosa has the highest mortality rate of all mental illnesses, with a number of these fatalities being due to people ending their own life. While we recognise this statistic and these symptoms may be alarming, we know that many of these symptoms are reversible and can be prevented from worsening with the right treatment.

Psychological consequences

Anorexia nervosa can also have many psychological symptoms. These can include the person feeling depressed or low in mood, feeling anxious, feeling numb or a dulling of emotions, obsessive thinking, poor concentration and attention, rigid thinking patterns, and a loss of confidence. Although some of these may have pre-dated the eating disorder (rather than being a consequence of the illness), many of these symptoms can improve with the right help and treatment.

Social consequences

Anorexia nervosa also tends to affect people's social lives. The person may struggle to engage with their friends and family, avoid social events (particularly those where food is involved), struggle to maintain relationships, and withdraw from hobbies they used to enjoy. Treatment and recovery can address these problems and help the person to regain a happy and fulfilled life.

"The feelings towards my anorexia fluctuated between infatuated love and intense hatred, as I realised I was losing myself along with my weight. No matter what people said, it was the wrong thing. I could feel myself being horrible to my loved ones who only wanted to help but my brain convinced me that they were out to take this feeling of lightness and power away from me, so I listened to it instead of them."

"I had a 'voice' in my head that shouted at me. It told me I was fat and worthless and that I was not allowed to eat because I did not deserve food. I thought I was in control of my eating, but it got harder and harder to ignore the voice."

"Anorexia felt like a comfort blanket. It was like no one anywhere could understand what I was going through, but while I had anorexia, I would be okay. I felt dependent on my eating disorder but also felt like it was giving me some sort of invisible power that no one knew about but me."

Binge Eating Disorder

Binge eating disorder involves someone having repeated episodes of bingeing, where they eat a large amount of food in a short period of time and don't feel in control of their behaviour. People tend to eat until they are uncomfortably full and may go to extreme lengths to access food – for example, eating discarded food or stealing food. Bingeing is extremely distressing for the person and often leaves them feeling a lot of shame. Unlike bulimia nervosa, someone with a diagnosis of binge eating disorder does not use compensatory behaviours such as purging after a binge.

Binges are often carried out in secret as people feel very ashamed of their behaviour. Many things may trigger a binge eating episode, but commonly they occur when a person is feeling uncomfortable or negative emotions, such as sadness, anger or loneliness. People with a diagnosis of binge eating disorder may also restrict their diet or put in certain dietary rules around food – this can also result in them binge eating due to hunger and feelings of deprivation. They may also struggle to eat in front of others. People frequently report feeling disgusted with themselves after the binge, and intense anxiety over what has happened, which can reinforce that cycle of negative emotions, restriction and binge eating again.

Physical consequences

There are several physical consequences associated with binge eating disorder. Eating large quantities of food can result in damage to the oesophagus and stomach. Additionally, people with binge eating disorder often become obese – this can be associated with Type 2 diabetes, arthritis, high blood pressure, gall bladder disease and sleep apnoea. Aside from weight gain, people may also experience problems with their mobility; asthma; and excessive tiredness. Binge eating disorder has an increased mortality rate and people are at a higher risk of ending their own life. While we recognise this statistic and these symptoms may be alarming, we know that many of these symptoms are reversible and can be prevented from worsening with the right treatment.

Psychological symptoms

Binge eating disorder can also have many psychological symptoms. These can include the person feeling depressed or low in mood, feeling anxious, feeling numb or a dulling of emotions, poor concentration and attention, feelings of guilt and shame, and a loss of confidence. Although some of these may have pre-dated the eating disorder (rather than being a consequence of the illness), many of these symptoms can improve with the right help and treatment.

Social consequences

Binge eating disorder also tends to affect people's social lives. The person may struggle to engage with their friends and family, avoid social events (particularly those where food is involved), struggle to maintain relationships, and withdraw from hobbies they used to enjoy. Treatment and recovery can address these problems and help the person to regain a happy and fulfilled life.

"Binge eating disorder felt embarrassing. I felt disgusting, and like I couldn't talk to anyone about it because they would deem that I just couldn't control myself. I felt ashamed and not worthy of help, as I thought I didn't have a 'proper' eating disorder where I was losing weight. I would go to supermarkets and buy entire baskets full of treats, while pretending to be on the phone at checkout talking to my friend about a party that would never take place. My levels of self-hatred rocketed with binge eating disorder and I became so distant from friends, family and anyone who tried to help that I would literally lock myself in my room. I felt so lonely, and as if the only thing that could fill that void in me was more food."

"Sometimes I just feel that I've lost all control, that nothing in the world can feel as bad as I do after a binge; then I just start worrying about my weight. It never goes away."

Bulimia Nervosa

Bulimia nervosa involves cycles of binge eating and purging. This means the person will eat large amounts of food in one go. This feels out of their control, and often the person will eat foods during the binge that they would usually avoid. After a binge, unlike someone with a diagnosis of binge eating disorder, someone with a diagnosis of bulimia nervosa will try to compensate for the binge, such as by making themselves sick, fasting, taking laxatives, or excessively exercising, for reasons such as feelings of guilt and shame, and concern about weight gain. These cycles are extremely distressing for the person. Someone with bulimia nervosa is often a "healthy" weight; therefore, their illness may be less obvious to those around them.

People with bulimia nervosa will often disappear after mealtimes in order to purge the food they have eaten. They are likely to be preoccupied with food, their weight and their shape, and may struggle with eating in front of others.

Physical consequences

Binge and purge cycles can cause blood sugar swings, which can lead to mood swings and risk of blackouts. People with a diagnosis of bulimia nervosa may also experience electrolyte imbalance due to vomiting or laxative misuse, with low potassium levels being particularly common; this has potential to cause heart rhythm problems. There may also be physical damage to the oesophagus, stomach and colon due to vomiting and laxative misuse. People often have swollen salivary glands (which look like mumps), dental enamel erosion (often picked up by dentists), and sore skin on the backs of their hands or fingers if these are being used to make themselves sick. Bulimia nervosa has an increased mortality rate and people are at a higher risk of ending their own life. While we recognise this statistic and these symptoms may be alarming, we know that many of these symptoms are reversible and can be prevented from worsening with the right treatment.

Psychological symptoms

Bulimia nervosa can also have many psychological symptoms. These can include the person feeling depressed or low in mood, feeling anxious, feeling numb or a dulling of emotions, poor concentration and attention, feelings of guilt and shame, impulsive behaviours, mood swings, and a loss of confidence. Although some of these may have pre-dated the eating disorder (rather than being a consequence of the illness), many of these symptoms can improve with the right help and treatment.

Social consequences

Bulimia nervosa also tends to affect people's social lives. People may struggle to engage with their friends and family, avoid social events (particularly those where food is involved), struggle to maintain relationships, and withdraw from hobbies they used to enjoy. Treatment and recovery can address these problems and help the person to regain a happy and fulfilled life.

"Bulimia felt like I was on auto-pilot – bingeing/restricting was the only way to try and numb how I was feeling. I knew everything that I was doing was illogical, but I couldn't stop; food was the only way to numb my emotions. Of course, this never lasted long and soon after the binge/guilt/restrict cycle would begin again. It was lonely and difficult to open to anybody because I barely understood it myself, let alone be confident enough to put it into words."

"I used to go to the food cupboard, fridge or freezer and eat as much as I could, as quickly as possible, to try to make myself feel happier and fill the hole I felt inside. Afterwards I felt physically and emotionally upset and guilty about all the food I had eaten, so I would make myself sick."

Other Specified Feeding or Eating Disorder (OSFED)

Sometimes someone's symptoms don't fit all the diagnostic criteria for anorexia nervosa, bulimia nervosa, or binge eating disorder, yet they are still seriously affecting them. These people may be diagnosed with "other specified feeding or eating disorder" (OSFED), which is just as serious as other eating disorders.

Signs and symptoms of OSFED may include any of the signs associated with anorexia nervosa, bulimia nervosa or binge eating disorder. For example, the person may restrict their diet, binge eat, and/or purge. The person may experience distress or guilt around eating, social withdrawal, tiredness, difficulty concentrating, and preoccupation with food, their weight and shape. Physical complications will depend on the behaviours associated with OSFED, for example, restriction and/or purging, and can be found in the information provided on anorexia nervosa, bulimia nervosa and binge eating disorder.

Since OSFED can take different forms, you may need to read through this guide to find the information in the sections on anorexia nervosa, bulimia nervosa and binge eating disorder that is relevant to your loved one's illness. Your loved one's clinician will be able to guide you and point out which parts are more relevant. Note that OSFED should be treated in the same way as the eating disorder it most closely resembles; therefore, there is no specific treatment section for someone with the diagnosis of OSFED.

"My eating disorder left me feeling out of control, lost, sad, insecure, cloudy and fuzzy, focused on nothing but darkness, food control and what I looked like rather than the happy things in life."

Avoidant/Restrictive Food Intake Disorder (ARFID)

ARFID is an umbrella term that encompasses a variety of eating disturbances, all of which involve the person avoiding or restricting their food intake in terms of overall amount and/or range of foods eaten.

The three most common drivers of this avoidance/restriction are:

1) Sensory concerns, such as taste, texture, smell, appearance of temperature.
2) Concern about the consequences of eating, for example, fear of choking or vomiting.
3) Low interest in eating.

People with ARFID can have one or more of these drivers at any point, meaning ARFID can present very differently across individuals.

ARFID differs from eating disorders such as anorexia nervosa and bulimia nervosa since beliefs about the person's weight and shape do not drive the avoidance or restriction. A diagnosis of ARFID would not be given at the same time as any other eating disorders; however, it could either follow or precede another diagnosis.

Physical consequences

Due to the varied forms ARFID may take, there are a range of potential physical consequences. For example, someone with ARFID may lose weight and become severely underweight, therefore leading to potential problems such as heart complications, kidney and liver problems, and electrolyte imbalances. Someone with ARFID may also develop nutritional deficiencies such as anaemia through not having enough iron in their diet. While serious, many of these symptoms are reversible or can be prevented from worsening with the right treatment.

Psychological symptoms

ARFID can also have many psychological symptoms. These can include high levels of anxiety, feeling depressed or low in mood, poor concentration and attention and a loss of confidence. Although some of these may have pre-dated the eating disorder (rather than being a consequence of the illness), many of these symptoms can improve with the right help and treatment.

Social consequences

ARFID tends to affect people's social lives. Someone with ARFID may struggle to engage with their friends and family, avoid social events (particularly those where food is involved), struggle to maintain relationships, and withdraw from hobbies they used to enjoy. Treatment and recovery can address these problems and help the person to regain a happy and fulfilled life.

"One of the hardest things is having the awareness... that a fear of food is irrational and not feeling able to do anything about it, especially with a lack of services out there to help adults or even just an understanding of what I'm going through."

"Constantly having to worry about food adds to other worries, especially when you know that people will question why I won't eat like everyone else and why I'm so "fussy". It's a lot harder than it seems to live like this."

"I feel unable to feed myself properly, and even if I do make something I'm constantly worried that I won't like it, so I'll have to throw it away which makes you feel even worse about yourself."

Common Myths Around Eating Disorders

Summary:

- Eating disorders are caused by a combination of things.
- They are not a personal choice, a diet, or someone being vain or attention seeking.
- Parents or carers do not cause eating disorders.
- Anyone can develop an eating disorder.
- People do get better.

Myth: Eating disorders are a choice.

Fact: Eating disorders are complex illnesses – there is no single cause. Instead they are thought to be caused by a combination of biological, psychological, and sociocultural factors. Eating disorders are extremely distressing for both the individual and their loved ones, and often are accompanied by feelings of shame. They require specialist treatment, but people can and do get better. Eating disorders are mental health disorders and are never a personal choice.

Myth: Parents are to blame for their loved one's eating disorder.

Fact: There is often nothing a parent or other carer could have done to prevent the eating disorder, but they are often best placed to help to create an environment that promotes and supports recovery. Although treatment may involve families changing certain behaviours, this is often because families have inadvertently fallen into routines that accommodate the behaviours that have come from the eating disorder, as opposed to them being at fault. It is crucial for parents and carers to receive support during the illness due to the demanding nature of supporting someone with an eating disorder.

Common Myths Around Eating Disorders

Myth: Eating disorders are someone being vain and seeking attention.

Fact: Although there is often an association between body dissatisfaction and eating disorders, eating disorders are not someone being vain or just wanting to look a certain way. Eating disorders are serious diagnosable illnesses; they are not a lifestyle choice, a phase, or someone being attention seeking. Often people diagnosed with eating disorders go to great lengths to hide the eating disorder and to keep it secret.

Myth: Someone must be underweight to have an eating disorder.

Fact: Often when people think of someone with an eating disorder, they think of someone who is significantly underweight. However, although weight loss is typical in anorexia nervosa, most people with an eating disorder stay at an apparently "healthy" weight or are "overweight". If the person does need to restore their weight, this is only one aspect of treatment, and being weight restored does not mean that the person is recovered. The thoughts and behaviours that come alongside the eating disorder also need to be addressed.

Myth: Eating disorders only happen to young girls.

Fact: Research shows that eating disorders do not discriminate – they affect people of all genders, ages, ethnicities, sexual orientations, weights, and socioeconomic statuses.

Myth: Eating disorders are a diet that has gone wrong.

Fact: Although for some people, one trigger for an eating disorder may be that they have been dieting, eating disorders are not "a diet that has gone wrong". They are serious mental health disorders.

Myth: People cannot recover from the illness as it is in their genes.

Fact: Although there is evidence that someone's genes contribute to the risk of developing an eating disorder, this does not mean that your loved one cannot recover. Genes are only one part of a complex mix of risk factors. Full recovery from an eating disorder is possible with the right help and support.

Summary:

- Sometimes people are worried about getting better because the eating disorder brings them some positives, such as making them feel in control or helping them to block out difficult thoughts or feelings.
- Someone with an eating disorder may feel very ashamed about it. This might make them try to keep their eating and other behaviours secret.
- Remember that the eating disorder is separate from your loved one, and it is the eating disorder that drives behaviours like being secretive or telling lies about what they have eaten.
- Someone with an eating disorder may also have other mental illnesses, or difficult thoughts and feelings. For example, they may be low in their mood or harm themselves.
- If you are worried about changes in your loved one's mood or behaviour, then speak to their treatment team.

Secretive and Resistant to Treatment

Eating disorders are often described as a 'voice' in the person's head. This 'voice' can be thought of as a bully – it can be extremely controlling and manipulative, and thrives on secrecy. It is therefore important to be aware of the ways in which the disorder may manipulate your loved one and the tricks this can lead to.

Some people have also described the eating disorder as being like a friend to them: something that protects them, soothes their anxiety, gives them a sense of control and achievement, and something to focus on in order to deal with other aspects of life. For these reasons, thinking about life without the eating disorder can be extremely scary. This can mean that when the eating disorder is challenged, the person may use more secretive or extreme behaviours as a way to try to hold on to the illness. Although this may seem like your loved one is getting worse, it may in fact be a positive sign since the eating disorder is being confronted.

The following list highlights common behaviours to look out for when supporting your loved one. It may be distressing to read or think about so remember you do not have to go through this alone. It is important for you to seek support for yourself, through ways such as talking to friends or family members, peer support (see the Resources section), or getting in touch with charities such as Beat. It is also important to recognise that it is the eating disorder driving these behaviours, rather than your loved one 'misbehaving' or being deliberately disobedient.

Deception – the controlling nature of the illness can often result in the person lying about foods they have or have not eaten, or behaviours they have or have not engaged in.

Hiding food – desperation not to eat often drives people diagnosed with restrictive eating disorders to great lengths during meal and snack times. This includes hiding food in their pockets, up their sleeves, and in shoes and socks, storing food in their mouths to spit out or spitting food into tissues, putting food on the floor or in plant pots, and feeding any pets.

Hoarding food – people who binge eat may store up and hide food in order to have a supply to binge on. They may then dispose of the food wrappers secretly to avoid anyone realising.

Falsifying weight – the process of weight restoration can lead to great anxiety in people with eating disorders and can result in behaviours such as drinking water prior to being weighed (water loading), and wearing weights or other items in order to create the illusion of increasing weight.

Obsessive exercise – the eating disorder may also drive someone to obsessively exercise as a way to 'burn off' calories or lose weight. Often this exercise may be disguised in ways such as finding another reason to climb the stairs, partaking in housework, standing up rather than sitting down, fidgeting, pacing, and wearing less clothing in order to shiver.

Purging – often people who purge can be very secretive about this, for example through vomiting in bags and hiding these, or turning on the shower to try to hide the sound of them being sick. They may have to flush the toilet multiple times to get rid of their vomit too. Purging may also come through the individual taking laxatives or diuretics.

Secretive internet use – certain websites and social media pages exist that promote eating disorders and encourage certain harmful behaviours; often these are referred to as 'pro-ana' or 'pro-mia' sites. Be aware if your loved one is being secretive over what they are looking at on the internet or if they are displaying behaviours such as hiding their phone screen. Some people may have multiple social media accounts to try to hide that they are interacting with potentially harmful content, so it is important to remain aware, even if you already monitor your loved one's social media profiles. The NSPCC offers information about internet safety for children that you might find useful (see the Resources section).

Separate From Your Loved One

Carers often report that the eating disorder seemingly changes the personality of their loved one. These changes can be different for each person, but may include the person becoming increasingly introverted or displaying outbursts of anger or violence.

It is important to remember that the eating disorder is separate from your loved one: it is the illness that is the problem, not your loved one, and neither they nor you are to blame.

Externalising the eating disorder - viewing it as separate to your loved one - can empower you to help distance them from the illness and challenge the eating disorder behaviours. This challenge to the eating disorder may lead to your loved one acting out of character, but this is often the illness reacting as it feels threatened.

By externalising the illness, you can also help your loved one to recognise their thoughts and behaviours as resulting from the eating disorder. To do this, it can be useful to address the eating disorder as distinct from your loved one. For example:

"What did the eating disorder say to make you feel unable to eat your snack?"

"What did the eating disorder say to trick you into purging after your dinner?"

"How does the eating disorder make you feel about yourself?"

Externalising the eating disorder can also help your loved one to feel less like they are being criticised or are to blame: you both recognise that it is the eating disorder.

"My parents were great at restricting [my exercise] and suggesting we did other things like go for a gentle walk or go out to a museum instead...they were very vigilant not to be seen exercising day in day out by me and adapted their own behaviour to show me that it was absolutely fine not to do so."

"Remember that the person suffering from the eating disorder is not their eating disorder. Have patience and try to not lose your temper at what might look like a blatant lack of reason on their part. An eating disorder is a complex mental illness and is very difficult to handle, but the person suffering is still your daughter, your son, your brother, your sister, your neighbour, your friend. Rather than reducing them to their eating disorder, remind them that they are so much more than it."

Externalising the eating disorder will not be helpful for everyone. Some people may feel that the eating disorder is part of them, rather than separate, and may struggle with questions such as those above or find them patronising. It could also feel dismissive of what is going on for the person. If this is the case, it could be helpful to explore this with your loved one and their treatment team, to find a dialogue that works for everyone.

Co-occurring Behaviours

Commonly, eating disorders do not occur alone and are instead accompanied by co-occurring behaviours or other mental illnesses. These may have been present prior to the eating disorder, for example, anxiety disorders, depression, self-harm, or obsessive compulsive disorder, but they could also occur following the development of the eating disorder. This can make eating disorders more difficult to diagnose, since the eating disorder may look like another mental illness. Two or more illnesses are known as "comorbid conditions".

Comorbid conditions and co-occurring behaviours do not mean that recovery is impossible. Co-occurring behaviours will often diminish once someone is in recovery from the eating disorder. For example, your loved one may develop ritualistic behaviours, such as repetitive checking or arranging items in a specific order, as an attempt to alleviate the anxiety of the eating disorder being challenged. They may believe that something bad will happen if they don't carry out these behaviours. This can mean the behaviours become worse as the person begins recovery. However, they will often reduce once the person is further along in their recovery journey.

It is also not uncommon for someone's mood to drop as they engage in treatment. Often eating disorders can numb a person's emotions or prevent them from experiencing certain thoughts or feelings. This can be due to "starvation syndrome". Starvation syndrome can occur if someone's food intake is poor, irregular or unbalanced, and so can affect people with any eating disorder diagnosis – it does not mean the person has to be underweight. As the person progresses throughout treatment and begins to eat more regularly and reduce any compensatory behaviours, difficult thoughts and emotions may rise to the surface. This can be a distressing time, so your loved one may require more encouragement that they are making positive changes and support in dealing with the difficult feelings, for example, through trying alternative coping mechanisms. If you are concerned about any changes in your loved one's mood or behaviours, it is important to raise these with your loved one's treatment team or main support worker.

Stages of Change

Summary:

- It can take time for someone with an eating disorder to want to get better and to change their behaviour.
- At first, your loved one might not realise that they have a problem.
- Gradually over time they will start to see that something is wrong and begin to want to change.
- Even after they have started to make changes, they may have times when they go back to their old behaviours. This can be difficult to watch, but you can learn from these setbacks and they can help strengthen someone's long-term recovery.
- This section explains the different stages your loved one may go through.

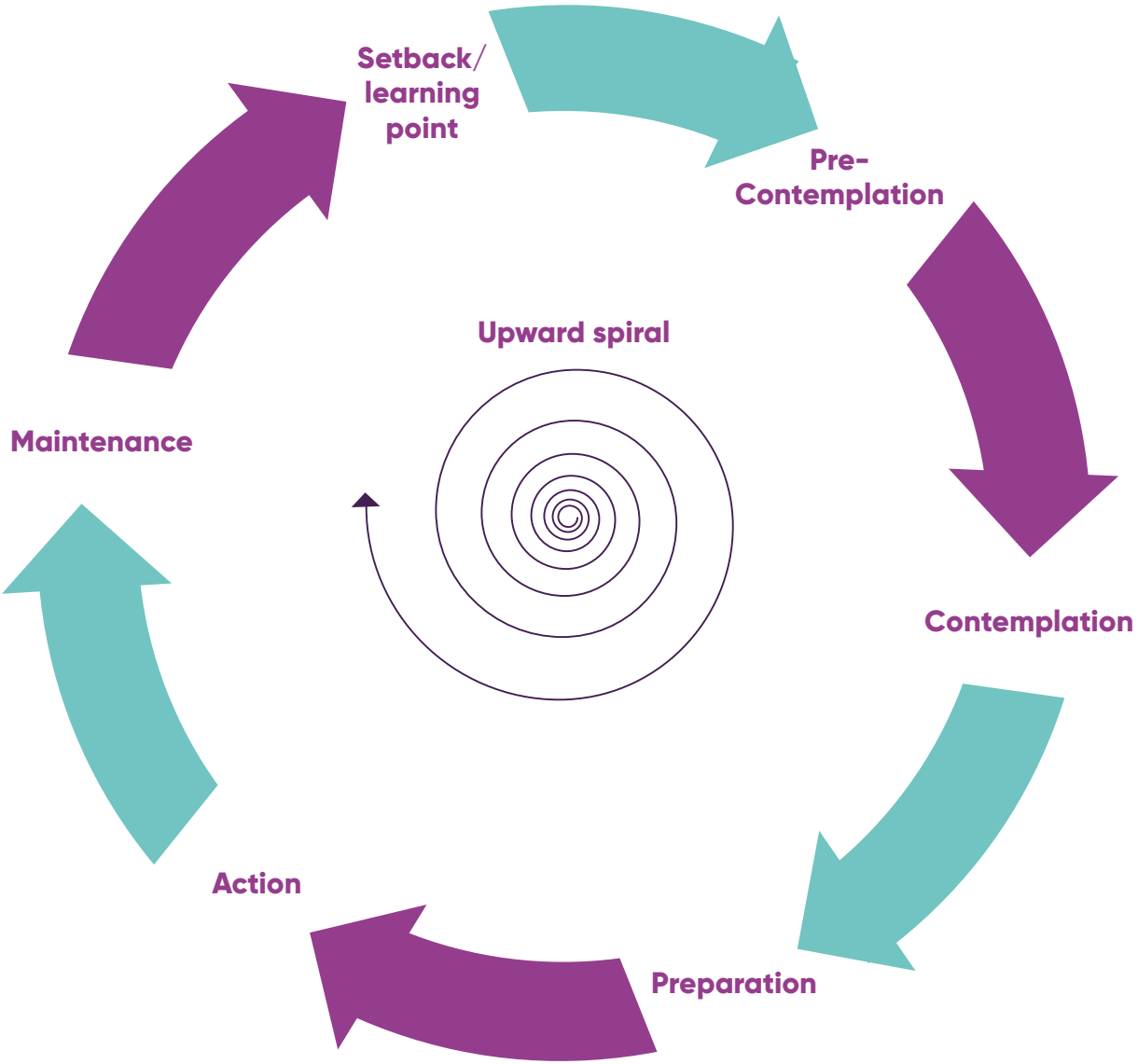
Despite how desperate you may be for your loved one to recover, it often takes time for people with eating disorders to seek and engage in treatment. This can feel very frustrating and difficult to understand. It is therefore important to manage your expectations when your loved one enters treatment. Unfortunately, there is no quick fix for an eating disorder and recovery takes time.

The 'stages of change' cycle can be helpful to understand more about where your loved one is in terms of thoughts around behaviour change, and what to expect. It highlights that although recovery is possible, it's not straightforward. Instead it involves ups and downs - setbacks can be used as learning opportunities, and can help your loved one to keep moving in an upward spiral towards recovery.

The cycle can also be helpful when thinking about where you are in terms of your own views about change - commonly carers report being in 'action' stage from the beginning of treatment, while their loved one is at the 'pre-contemplation' stage. This can cause conflict, so it is important to try to be compassionate in understanding where your loved one is at.

Although the 'stages of change' cycle is one way of thinking about recovery and behaviour change, it is important that the person is both encouraged and supported to make changes early on in treatment.

Stages of Change



The Cycle of Change, adapted from work by Prochaska & DiClemente (1983)

More about each stage:

1. Pre-Contemplation Stage

Often people enter treatment while in the pre-contemplation stage – this means that they are likely to be in denial that there is a problem and may be hostile to the suggestion that anything is wrong. Someone may stay at the pre-contemplation stage for a length of time; however, your loved one's clinician will work to manage this and help them to still make changes early on in their treatment. If your loved one is in pre-contemplation mode, it is likely that there will be greater resistance to treatment, and you may have to take more of a direct role in supporting them with making changes.

As a carer, the pre-contemplation stage can be both scary and frustrating. Try to stay calm when speaking to your loved one. Remember that people can and do recover from eating disorders, even though that feels quite distant during this stage. It can be beneficial to gently try to help your loved one to realise the need for change, and to see the bigger picture of what is going on for them. For example, someone may state that the eating disorder is giving them control, so it could be useful to softly challenge this by questioning whether it is them or the eating disorder in control.

2. Contemplation Stage

During the contemplation stage, your loved one will recognise that there is something wrong. They may begin to consider making a change, but not yet be ready to take this further and take action. This can be confusing for them as they can begin to see the benefits of making a change, yet the eating disorder is serving a function and they are not ready to let this go. Often the eating disorder is thought of as the person's friend and something that is keeping them safe, so letting this go of this can be extremely scary.

It can be helpful to encourage your loved one to share their thoughts and feelings about the eating disorder with you, and let them know you hear what they are saying. If your loved one describes the illness as a friend, you may also wish to gently explore how good a friend it is if it is harming them and resulting in their life being consumed by the upsetting thoughts and feelings. Try to encourage and strengthen your loved one's beliefs that there is a need for change, and let them feel in control of this decision. It can be tempting to impose your own beliefs on why they need to change, but this can lead to increased resistance from the eating disorder.

3. Preparation Stage

During the preparation stage, your loved one will decide that they want to change their behaviours, and will be getting ready to do this. They might look to you for support and encouragement on the next steps to take.

Here, you could help them to make a plan for how they are going to make these changes and what next steps are needed (for example, the introduction of feared foods or reduction in certain behaviours). Talk to your loved one about how you can best support them with these steps and what to do if they are struggling to implement these changes. Reassure your loved one that you will be by their side and are there to support them so they are not doing this alone.

4. Action Stage

During the action stage your loved one will begin to make the changes needed for recovery. They may be engaged in treatment and working hard to change their behaviours.

It is likely that these changes will be difficult for your loved one to make and will result in distressing thoughts or feelings. Some people have reported feeling conflicted between the voice of the eating disorder and the part of them that wants to recover. Remind your loved one that you are there for them, and offer reassurance in those times when they feel conflicted about what to do.

5. Maintenance Stage

During the maintenance stage your loved one will work on integrating what they learn in treatment into everyday life, and learn to form an identity away from the eating disorder. They are likely to make a plan for what to do if they feel that things are slipping in the future, and how to recognise this.

It can be helpful to discuss with your loved one any potential triggers for the future, and to support them in learning to live their life away from the illness. It may be helpful to reflect on any changes to your relationship throughout the recovery process and think about how these may be addressed going forward. It is important to remember that although setbacks may happen, people can and do recover from eating disorders. Take time to work on your own self-care too; supporting a loved one with an eating disorder is not easy.

6. Setbacks/ Learning Points

Recovery is not a linear process, and it is common for setbacks (commonly referred to as lapses and relapses) to occur. Lapses tend to refer to small setbacks or slips, whereas releases tend to refer to a bigger setback in terms of thoughts and behaviours. Although these can be extremely difficult to watch, setbacks can be an opportunity to learn (learning points) and move forward in strengthening recovery. Despite how it may feel, your loved one is never back to the start.

During this stage, it can be helpful to let your loved one know that you are there to support them and that these setbacks are a normal part of the recovery process. Setbacks do not mean that recovery is not possible – sometimes people have to go through this cycle of change a few times before they are able to maintain their recovery.

Summary:

- Families, partners, friends and other carers can play an important part in helping their loved one to get well.
- How you support your loved one will vary according to their treatment and your relationship with them.
- Because supporting someone with an eating disorder can be so difficult, you should be offered an assessment by your loved one's eating disorder service to see whether any additional support would be helpful.
- This section helps explain how you can best help your loved one, while looking after yourself at the same time.
- The Resources section of this pack also suggests lots of helpful resources.

"My family were absolute saviours throughout my eating disorders. They took time to research and read up on what I was going through, made sure they asked the doctors and dietitians lots of questions and were an unwavering support system. Even at times when I felt so low that not even they could cheer me up, my parents and siblings ensured I knew that they were there even if that just meant sitting in silence or trying to take my mind off things."

Families, partners, friends and other carers can play an essential role in the recovery of their loved one, through ways such as:

- Helping the person to access treatment and to attend sessions.
- Ensuring that evidence-based treatment is provided.
- Supporting their loved one with meals and snacks.
- Helping their loved one to manage urges.
- Providing a recovery-focused environment.
- Helping their loved one to explore who they are and what they like doing, if the eating disorder has become their identity.

The way you can provide support will vary based on your loved one's treatment and your relationship with them. Below we will discuss the role of a carer during recommended first approaches to treating eating disorders.

A Carer's Role During Eating-Disorder-Focused Family Therapy

Anorexia-nervosa-focused family therapy (FT-AN) and bulimia-nervosa-focused family therapy (FT-BN) is recommended for adolescents diagnosed with anorexia nervosa and bulimia nervosa. You may hear other terms such as "Family Based Treatment" (FBT) and "Maudsley Family Therapy", but these are all variants of family therapy and the NICE guideline does not distinguish between them. If you have questions about the model of treatment that has been offered to your loved one, we would suggest asking their clinician.

Eating-disorder-focused family therapies emphasise that families do not cause eating disorders, but instead they can be a vital resource to help their loved one recover. Families, in particular parents, are asked to take a central role in managing their loved one's food intake and the prevention of disordered behaviours, such as excessive exercise, binge eating and purging. This will mean supervising each meal and snack, and being with them after these to prevent compensatory behaviours. Over time, this role will start to shift, and the person will start to manage some of their own snacks and meals, as appropriate.

Although the carer's role is intense, your loved one's clinician is there to support and guide you through this. Specific resources that help support carers through family therapy can be found in the Resources section at the end of this pack.

"At the time, it was really difficult to have my parents in control of my eating during FBT (Family Based Treatment). I fought against them as the eating disorder was screaming at me not to eat. However, I'm now so grateful for their persistence. They were empathetic, yet firm and reassured me that it was the eating disorder we were all fighting against. They helped distract me after mealtimes when the eating disorder made me feel immensely guilty for what I had eaten."

A Carer's Role During Individual Eating-Disorder-Focused Cognitive Behavioural Therapy

Eating-disorder-focused cognitive behavioural therapy (CBT-ED) is commonly recommended in the treatment of eating disorders. The role of carers supporting a loved one during CBT-ED varies depending upon the nature of the relationship, where the person is in their recovery, and the degree of involvement the patient would like. This lack of structure can be difficult for carers, particularly if they have been closely involved in their loved one's treatment, as is the case during family therapy. You are still able to play a vital role in your loved one's recovery – for example, through ensuring a recovery-focused environment and supporting your loved one through the challenges of recovery.

During CBT-ED, the responsibility for your loved one's eating behaviours lies with them. Firstly, treatment will focus on establishing regular eating, and ensuring that patients are eating three meals and two or three snacks a day without the use of compensatory behaviours (if present). Your loved one becomes responsible for choosing what to eat and for sticking to their plan without using eating disorder behaviours. This is an aspect of treatment where your loved one might value your support, so it could be helpful to talk to them about what they would like your help with.

As CBT-ED progresses, your loved one will work with their clinician to understand the factors maintaining the eating disorder, such as following strict dietary rules and over-evaluation of weight/shape, and the clinician will support them to address these. This may involve introducing avoided foods, learning to deal with triggers, and addressing certain behaviours. The way in which you are best able to help will vary – for example, for some people, having someone to eat with or to be with during or after a difficult situation can be immensely valuable and can lessen distress.

"They were particularly good around the dinner table, which is the hardest place to be for anyone with an eating disorder. They weren't judgemental of how little or how much I would eat and kept the focus off the actual food at all times. Mum started coming to see me in my room every night after dinner to ask how I felt, and if I was feeling anxious, she would stay with me and watch a film or chat or read until the feeling had passed."

A Carer's Role During Guided Self-Help

Guided self-help is one recommendation for the treatment of binge eating disorder. The role of carers supporting their loved one during guided self-help varies depending upon the nature of the relationship, where the person is in their recovery, and the degree of involvement the patient would like. This lack of structure can be difficult and result in uncertainty; however, you are still able to play a vital role in your loved one's recovery. Ask your loved one what would be most helpful for them during this time. For example, it could be that you are able to support them in planning for and shopping for their meals and snacks, or it may be that you can help them to overcome the urge to binge if that arises.

"My mum always listened to my fears around certain foods and did her best to be flexible with food. I told my parents that evenings were the times that I binged the most and so they sat with me and watched TV till late to distract me. I really appreciated the support and we still have such a good relationship – if not stronger – now that I am recovered. It's always worth asking if you can do anything to help."

Support for Yourself Through Treatment

The NICE guideline states that family members or carers should also be offered an assessment to establish whether additional support would be helpful. This could be for practical help or for your own mental wellbeing. If you have not had this offer, or if your needs change, you should discuss this with the clinician working with your family.

Beat's Helpline and online peer support groups are also available seven days a week if you need to talk to someone supportive who is not directly involved in your loved one's treatment.

It could be helpful to also think about who or what else would be beneficial in supporting you through this period. Are there any friends or family who can offer you support, whether this is helping to look after your loved one, or doing the cleaning so you don't have to? Would seeking help from your own GP be helpful? If you work, are you able to receive compassionate leave from your employer? Often caring for someone who has been diagnosed with an eating disorder can feel extremely isolating and exhausting, so try to be kind to yourself and accept help when it is available.

Confidentiality

Confidentiality is an essential part of maintaining the trust between a patient and their healthcare professional. However, forcarers, confidentiality can often feel like a barrier between themselves and their loved one, and something that is preventing them from knowing about their loved one's care and wellbeing. This can be extremely frustrating, especially at a time when you are concerned about your loved one. However, respect for patient confidentiality shouldn't mean healthcare providers don't listen to or communicate with you. You should be given enough information by healthcare providers to be able to provide effective care. For instance, although you won't be able to be told specifics of your loved one's treatment or their progress if they have requested these to be confidential, you should receive good quality information about eating disorders in general, including their symptoms, treatment and advice on how to manage them.

You are also entitled to see a professional for your own support and to express any concerns you may have – anything you share with a professional should also be treated confidentially.

Your Role in Supporting Your Loved One's Wider Recovery Journey

Treatment is only one aspect of your loved one's recovery journey. There are several ways outside of your loved one's treatment programme that you can play a vital role in helping them to get better. This can range from being a listening ear, to going to the supermarket with them and supporting them after mealtimes. And remember, one of the most important things you can do for your loved one is look after yourself.

"What helped me most was my loved ones just being there for me. It was a tough time for family who didn't know what to do or what to say. I suspect they felt like they were treading on eggshells all the time around me. A couple of friends just explained they were at the end of the phone if I needed them."

General Support

- Acknowledge to yourself that you are not to blame.
- Acknowledge to your loved one that they are not to blame.
- Ask your loved one what you can do to help – for example, helping them to stick to regular eating, putting in boundaries following mealtimes, having a space to talk about how they are feeling. Your loved one may respond that you can just "leave them alone" or that you can't do anything to help, so here it can be helpful to remind your loved one that you can hear their distress and how difficult things are, and you are there if they need you.
- Recognise how distressing the illness is for your loved one.
- Educate yourself about eating disorders where you can.
- Ask your loved one how they are feeling and what they are thinking, rather than making assumptions.
- Avoid discussing weight, shape, food, and diets in front of your loved one, and model a balanced relationship with your own food and exercise.
- Recognise any 'accommodating or enabling behaviours' – behaviours that you do to help reduce your loved one's distress from the eating disorder, for example, cleaning up vomit or cooking different meals for them, but that collude with the disorder and cover up the negative consequences of the behaviours.
- Think of social events that don't revolve around food or exercise, such as trying out different crafts, or playing board games.
- With your loved one, come up with a list of distraction techniques that can be used when your loved one is struggling, for example after mealtimes or if they have an urge to binge eat.
- Take time to discuss topics outside of the illness and treatment – this can feel very tricky but your loved one is still there despite the eating disorder.
- Help your loved one try out new hobbies or return to hobbies that they used to enjoy. If your loved one enjoyed sports or exercise prior to developing the eating disorder and this became a problem, ensure that you consult with their medical professional about the best way to manage this.
- Remind yourself that things can change and reassure your loved one that recovery is possible.

"In therapy I was advised to make a distraction box full of activities (books, drawings, crosswords, anything to take your mind off things) for when I wanted to act on negative thoughts. This was a great tool, especially since avoiding acting on thoughts is one of the hardest parts of recovery."

Dealing With Meal Preparation

Ensure you have everything you need for the planned meal to avoid last-minute changes that could increase anxiety.

If you are eating together, plan with your loved one what you will be eating, at what time, who else will be there, and think about portion sizes.

If your loved one is struggling to food shop due to anxiety about things such as nutritional labels, either offer to do the shopping for them or go together to help support them.

Some people who binge eat may have difficulty with the abundance of food in supermarkets; therefore writing a list and shopping together for this can be helpful. Food shopping via the internet can also be helpful for some people.

Often during treatment, avoided foods will need to be reintroduced. Planning the day and time that this will be along with the treatment team, and shopping for it together, can help this process feel more in your loved one's control.

When shopping, multipacks of avoided or fear foods can seem overwhelming, particularly if it is a food that the person tends to restrict or binge on. Buying the food as a single item rather than part of a multipack could be more manageable for your loved one.

Dealing With Mealtimes

Ask your loved one what would be most helpful during the mealtime. Some examples of things that have helped other people are having the television or radio on, colouring tablecloths, doing a puzzle or being involved in conversation.

Keep conversation neutral at mealtimes, so avoid discussing topics such as diets, exercise or how treatment is going.

Help to distract your loved one before, during and after mealtimes.

In people with restrictive eating disorders, eating regularly again can bring about physical discomforts such as stomach pain and feeling full very quickly – it is important to follow the advice of your loved one's treatment team in response to this. This may require supporting your loved one with pushing through this discomfort and continuing to eat regularly.

Evening times are often the most vulnerable time for people who binge eat – ask your loved one what you can do to help with this, or at other times that they may find difficult.

"My parents also helped avoid situations that they knew would spark my food anxiety or exercise obsession - if we were invited round to neighbours' or friends' for dinner, for example. They would always plan ahead or have a quiet word with the neighbours so that I felt entirely secure, but not like they were interfering."

Be Mindful of the Language You Use

The eating disorder can cause your loved one to misinterpret what is being said to them, which can leave you unsure of what to say and concerned about upsetting them.

Below are some examples of things that carers may innocently say, and what the eating disorder may cause their loved one to hear instead. More examples of this can be found in the book *ED Says U Said: Eating Disorder Translator* by June Alexander and Cate Sangster, and on Beat's blog posts (see Resources section).

It could be helpful to share this section with wider family members and other people likely to talk to your loved one, to help them to understand more about the eating disorder and avoid upsetting conversations.

"Just eat normally."

What may be heard: You're not trying hard enough, it's not difficult to eat, it's your fault, you need to get over this.

Positive alternative: To outsiders it may seem like people with eating disorders just need to eat, or just need to stop purging or binge eating. This is not the case – eating disorders are not a choice but are severe mental illnesses that the person needs supporting through. It is therefore important to acknowledge to the person that you know it's difficult for them, and you are there to support them.

"You look well."

What may be heard: You look fat, you have gained weight, you're greedy, you're healthy now so things are easy for you.

Positive alternative: Any comments to do with your loved one looking "healthier" or "better" are often taken to mean they have put on weight. Instead of commenting on their physical appearance, try to ask the person how they are, or compliment something about your loved one that is unrelated to their body such as an item of clothing or an accessory.

"I wish I had your control."

What may be heard: You are lucky to have an eating disorder, you are in control of the illness, it's a good thing to be obsessive with food, weight and shape.

Positive alternative: Often eating disorders are used as a coping mechanism and a way to feel in control. However, when someone has an eating disorder the illness controls them and fighting against the thoughts and behaviours is extremely difficult. Avoid commenting on the eating disorder as if it is the person's choice.

"You just need to stop eating so much."

What may be heard: You are fat, you are greedy, binge eating isn't a problem, you are making this up, it is easy to stop binge eating.

Positive alternative: Acknowledge how difficult things are for your loved one, and how distressing the eating disorder must be. Let them know that you are there to support them.

"Get well soon."

What is heard: It's easy to get over this, you aren't trying hard enough, you are being a burden, hurry up and get better.

Positive alternative: Reassure your loved one that although you recognise how difficult things are for them, you are there for them and will continue to be throughout. Let them know how proud you are of them for challenging the illness.

"I wish I had your body."

What is heard: You are lucky to have an eating disorder, you are just doing this to look a certain way, you need to keep doing the disordered behaviours.

Positive alternative: Try to avoid discussing your own weight and shape in front of your loved one as it can be unhelpful for them to hear. Instead focus on topics away from body image, food or exercise.

"I can easily finish a packet of biscuits so know exactly how you feel."

What is heard: Everyone eats that way, you don't have a problem, it is normal to binge eat, you don't deserve support.

Positive alternative: While many people will overeat on occasion, and this may be triggered by difficult emotions, this is not the same as having binge eating disorder. Binge eating disorder is extremely distressing for the person and involves the person feeling a loss of control while eating a much larger amount of food than most people would eat in similar circumstances. It is good to be understanding, but important to avoid trivialising what the person is going through.

Dealing With Emotional Outbursts and Crisis Situations

Due to the nature of the eating disorder, often things get worse before they get better. There may be times when your loved one displays emotional outbursts, such as anger or aggression. Often this is because the eating disorder feels challenged and trapped, for example at mealtimes or if you prevent them from acting on an urge. Here, your loved one's coping mechanisms are being taken from them – this can be extremely scary to them and lead to them feeling threatened. Emotional outbursts may also result from your loved one feeling frustrated with the eating disorder, yet conflicted by this – this can leave your loved one feeling helpless and scared, which can be expressed through violent outbursts.

Although the anger and any violent outbursts are often caused by the eating disorder, this does not make it acceptable. You know when the eating disorder has gone too far, and you can choose not to accept behaviours different to those you would accept from another person. Although it is difficult, try to take a breath and stay calm so as not to escalate the situation. Think about how best to ensure that you, your loved one and anyone else present are safe, and put into place the necessary actions. It is important to think about how you are going to deal with emotional outbursts and be ready for them before they happen. You will probably find it useful to discuss this with your loved one's clinician.

Once the situation begins to calm down, you may want to ask your loved one to explain what is going on for them, as you can see that they are upset. Show that you have heard their concerns or difficulties by repeating some of the words your loved one has used and reflecting these back to them. For instance, if they have shouted at you: "I would be fine if you backed off. You just make things worse," you could reply with "What can I do so that I'm not making things worse?" This signals to your loved one that you have heard them and are listening.

Witnessing emotional outbursts can be extremely distressing, and especially hard if the anger appears to be directed at you. Remember, through challenging the illness you are helping your loved one to fight the eating disorder. After the situation has calmed down, it is important that you take time to look after your own needs. It might be that you explain to your loved one that you love them and don't blame them for

how they reacted, but that you are going to take some time to go to another room to call a friend, or to go for a walk to look after your own wellbeing. Here you are letting them know that you love them, but also recognising the importance of self-compassion and modelling this to them. You have had to deal with a tough situation so it is important to build yourself back up again after this.

Empowering Yourself to Support Your Loved One

Caring for someone who has been diagnosed with an eating disorder can feel overwhelming and exhausting. Carers often report that supporting their loved one affects their own physical and mental health. It is therefore important that you have your own support network and positive coping mechanisms. Where possible, ensure you have time away from your loved one to do things you enjoy and gain support from others – carers sometimes say they feel this is selfish, but in fact it will strengthen you and help you get through the difficult times.

Every carer's experience of supporting their loved one is individual, as is the way they manage their own wellbeing. The following ideas have been suggested by other carers who have supported someone with an eating disorder diagnosis:

- Seek support for yourself, whether this is in the form of formal counselling, chats with friends, peer support or support groups (see the Resources section). Remember the saying "You can't pour from an empty cup" – you need to look after your own wellbeing and resources to best support your loved one.
- Take time to manage your own expectations of recovery. It can be hard not to take it upon yourself to immediately "fix" the problem; however, while recovery is entirely possible, the path is often a slow one and not a straight line. The desire for a quick fix can become overwhelming, but it's also impossible. Accepting what is happening and recognising that some things are outside of your control will lessen the pressure you're placing on yourself.
- Remind yourself that everyone makes mistakes; there will be times when you reflect that a situation could have been handled better, or you regret something that you have done or said. Rather than berating yourself for these, acknowledge them and learn from them – you are dealing with a very difficult situation and are doing your best.
- Write a list of ways in which other people can help you – this may be practical day-to-day things, or direct help with supporting the person you're caring for. Writing a list allows you to ask for help with specific tasks based on the interests and capabilities of your own support network, or for them to choose which things they feel most equipped to help out with. Don't be afraid to ask for help, as most often people will want to support you.
- Take time to reflect upon how you are feeling and your own emotions, as a way of understanding your own needs. It might be that you are struggling to enjoy things you used to, so this could be a sign that you should speak to your own GP about support they can offer.
- Give yourself permission to meet your own needs. Think about what you enjoy or that makes you feel better – perhaps a hobby, exercising, seeing friends or practicing mindfulness. You will be able to be more supportive of your loved one if you have had a chance to focus on your own wellbeing.
- Break down the areas of stress in your life into chunks that feel more manageable to consider. Rather than feeling like everything is overwhelming, are there aspects of the stressful situation that you are able to think of solutions for?

- If you are concerned about an upcoming conversation, for example, with your loved one's clinician, write down a list of questions or concerns you have prior to the meeting. This will help you to feel more prepared for the conversation. It could also be helpful to let the other person know that you wish to talk to them prior to the discussion, so that you are not rushed.
- Work on communicating constructively through the use of "I" statements, rather than "you" statements which can feel accusatory and result in the other person being defensive.
- Consider what will help you feel more grounded and aware of the present moment, rather than feeling like everything is spinning around in your head. Experiment with different grounding techniques. For example, having a small object available to touch, such as a stone or a crystal, can help remind some people that they are in the present. Breathing exercises, such as those found on YouTube videos or apps, can also be a useful resource to help people to let go of tensions and bring them back into the present moment.
- Practice self-compassion. You did not ask to be in this situation nor are you to blame for it. Exercises to help you practice self-compassion can be found on the internet, and there are some examples in the Resources section.

To hear from parents and carers about the importance of taking time out to look after yourself while supporting your loved one, have a look at the video "Looking after yourself" on CaredScotland's website – see the Resources section.

Financial Support

Carer's Allowance can provide financial support to carers who are finding it difficult to work as a result of looking after their loved one. You can also check your local council for services that support parents, carers and people with mental health difficulties to maximise any income through support and advice. Charities, Citizens Advice Bureau and carer support networks can provide further information, and some will support you to apply for Carer's Allowance. If your loved one is a university student, then they can apply for Disabled Students' Allowances (DSAs) to see if they are eligible for financial support to help cover some of the extra costs due to the eating disorder. Information about carers' charities can be found in the Resources section.

Telling Others

Eating disorders, and mental illnesses in general, are often surrounded by stigma and misconceptions. This may make telling people about your loved one's eating disorder more difficult. In some cases, you may not need to explain the exact nature of the illness to other people, especially if they are not likely to meet your loved one. However, when it is important to let people know about the eating disorder, Beat's website found in the Resources section at the end of this pack can help you to do this.

Once people are aware of the situation, you might find they have questions about your wellbeing and that of your loved one. If this becomes difficult for you or feels overwhelming, you could ask someone else to keep people updated; it is important to do what feels manageable to you. If there are people who want to help but whose close involvement is not appropriate, you could ask for their help with day-to-day tasks. This could also involve asking for help with a sibling or child or young person where applicable, for example, giving them a lift to a club they attend, or taking them to the cinema for some time away from home.

Supporting Others

As well as supporting your loved one with recovering from an eating disorder, it may be that you also have other loved ones who require your support. This might be a child, a relative, a friend or a partner, for example. This can be extremely exhausting, and lead to people feeling like they are not doing a 'good enough' job. If you're feeling this way, it's important to recognise the huge challenge you are facing, and the hard work you putting in.

Where possible, recognise that you're not alone. Ask for support and accept it if it's offered, so you can share the burden with others. If the person you are also supporting is a child, it could be helpful to speak to their school about what is going on for them at home and any extra support they may need.

Supporting Siblings

Siblings can take many roles in their loved one's recovery. This may involve attending formal treatment sessions, or helping more generally, such as joining in an activity to support their sibling before or after mealtimes. Although siblings may want to be involved in this way, it is important to make it clear to them that they are not responsible for their loved one's treatment or recovery. It can also be helpful to make clear to the sibling that they can have space away from home if needed – such as spending an evening at a friend's house or going to see a film at the cinema.

Siblings can feel a range of confusing emotions about the eating disorder and the impact it has on the family. They commonly report fearing that their sibling will never recover and will die, so it is important to try to reassure them that recovery is possible, but sadly it is not a quick process. Reassure them that you are all working to support your loved one as best you can. Siblings can also report feeling guilty for living their life, but it's important to encourage them to keep having fun and seeing their friends; let them know that their sibling's recovery is not their responsibility. Often siblings can feel anger at the situation, which is something you may also have experienced. Try to help them direct this anger at the eating disorder, rather than their sibling, and reassure them that it is normal to feel this way.

Siblings commonly report that they would have appreciated having more information about the illness, so it can also be beneficial to ask them if they have any questions about what is going on and to let them know they can come to you if they do. It may be that it would be helpful to have a close friend or relative to talk to the sibling too, since they may wish to protect you and so not be open about how they are feeling or concerns they have. Beat's leaflet 'Caring for Someone with an Eating Disorder (for Under 18s)' may be useful to show them. CaredScotland also has a self-help pack for siblings of a young person with an eating disorder. See the Resources section for details of these.

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Evidence-Based Outpatient Treatments: Children and Young People

Summary:

- The type of treatment offered to your loved one will depend on things like their age and the sort of eating disorder they have.
- Their eating disorder service will use evidence-based guidelines when deciding which treatment to offer.
- This section describes the treatments your loved one is most likely to be offered.
- If you have any questions about your loved one's treatment, speak to their clinician or main support worker.

The type of treatment offered will depend on factors such as your loved one's age and diagnosis. The National Institute for Health and Care Excellence (NICE) guideline for eating disorders provides evidence-based recommendations for the treatment that your loved one should be offered. Based on this guideline, clinicians will start with the option that they believe will work best for an individual, but they may have to try more than one treatment before they find what best suits your loved one. If you have any questions about the treatment option your loved one has been offered, speaking to your loved one's clinician or main support worker is likely to resolve these.

The following pages are a list of NICE-recommended treatments. This list is comprehensive and may include elements that are not relevant to your loved one. Rather than feeling like you should read it all, focus on the treatment types that may be relevant for your loved one and read at your own pace.

Note that OSFED should be treated in the same way as the eating disorder it most closely resembles; therefore, there is no specific mention of OSFED. Additionally, the NICE guideline for eating disorders does not currently include recommended treatments for ARFID. This does not mean that it does not need specialist help and support. Due to the varied presentations that ARFID can take, your loved one can be treated by several different services and a range of professionals, including eating disorder services or general mental health professionals. Treatment should be tailored to the specific difficulties your loved one is having and the factors maintaining these.

Eating-Disorder-Focused Family Therapy

Eating-disorder-focused family therapy (FT-ED) is recommended by the NICE guidelines as the first treatment for children and young people diagnosed with anorexia nervosa (FT-AN) or bulimia nervosa (FT-BN). Eating-disorder-focused therapy is also commonly used to support children and young people diagnosed with ARFID. You may see terms such as "Family Based Treatment" (FBT) and "Maudsley Family Therapy" – these are all variants of family therapy, and the NICE guideline does not distinguish between them.

Eating-disorder-focused family therapies emphasise that families do not cause eating disorders, but instead they can be a vital resource to help their loved one recover. Families, in particular parents, are asked to take a central role in managing their loved one's food intake and the prevention of disordered behaviours, such as excessive exercise, binge eating and purging. This will mean supervising each meal and snack, and being with them after these to prevent compensatory behaviours. Where necessary, the family will work with the person to support them with weight restoration. Once conflict around eating is reduced and, where required, a minimal level of weight restoration is achieved, control is gradually returned to the individual and they will begin to manage some of their own snacks and meals, as appropriate. Eating-disorder-focused family

therapies tend to include at least one session where the family have a meal in the therapy room with the support of the clinician.

- For the treatment of anorexia nervosa, FT-AN typically consists of 18 – 20 sessions over one year.
- For the treatment of bulimia nervosa, FT-BN typically consists of 18 – 20 sessions over six months.

Individual Eating-Disorder-Focused Cognitive Behavioural Therapy (CBT-ED)

CBT-ED is recommended for children and young people diagnosed with anorexia nervosa, bulimia nervosa or binge eating disorder. CBT-ED is also commonly used to support children and young people diagnosed with ARFID. In children or young people diagnosed with anorexia nervosa or bulimia nervosa, CBT-ED is recommended if family-based therapy is unacceptable or ineffective. In children or young people diagnosed with binge eating disorder, CBT-ED is recommended if guided self-help is unacceptable or ineffective, or if group CBT-ED is unavailable or declined. You may see the term "Enhanced Cognitive Behavioural Therapy (CBT-E)" being used – this is a variant of CBT-ED, and the NICE guideline does not distinguish between them.

CBT-ED is a talking therapy specifically for people diagnosed with an eating disorder, and is designed to be delivered on an individual basis. The idea behind to CBT-ED is that a person's thoughts, beliefs and behaviours interact, and so supporting the patient to change their disordered behaviours will result in changes to their thinking.

During CBT-ED, the clinician and patient work together to create a personalised treatment plan that addresses the factors maintaining the patient's eating disorder. Through treatment, strategies are put in place to help change the patient's disordered thoughts and behaviours. For example, the patient is asked to self-monitor what they eat and drink, and how this made them feel. This aims to help patients become more aware of what is happening in the moment, so that they can begin to challenge any disordered thoughts, and make changes to behaviours that previously seemed out of their control.

- For patients diagnosed with anorexia nervosa, CBT-ED typically involves 40 sessions over 40 weeks.
- For patients diagnosed with bulimia nervosa, CBT-ED typically involves 18 sessions over six months.
- For patients diagnosed with binge eating disorder, CBT-ED typically involved 16 - 20 sessions.
- Typically, sessions are twice weekly for the first few weeks.

"CBT and various counselling techniques helped unconsciously plant some tools to help me. Teaching myself to eat a healthy balanced diet and about proper nutrition was also helpful."

Adolescent-Focused Psychotherapy for Anorexia Nervosa (AFP-AN)

AFP-AN should be considered for children or young people diagnosed with anorexia nervosa if FT-AN is unacceptable or ineffective. It is based on the idea that the eating disorder is an unhealthy mechanism for coping with the demands of adolescence; the goal of treatment is to identify these issues and help the person to learn healthier coping skills.

AFP-AN typically consists of 32 – 40 individual sessions over 12 – 18 months, alongside up to eight 'collateral meetings' in which family members meet without the patient at critical times in treatment. The collateral meetings allow the clinician to support the family in helping their child to change behaviours in the home environment, as well as educating the family about the illness and recovery.

AFP-AN aims to empower the adolescent to make changes, rather than giving parents direct responsibility for their child's nutrition.

Guided Self-Help

Guided self-help is recommended for children and young people diagnosed with binge eating disorder. It uses cognitive behavioural self-help materials designed specifically for eating disorders, and should be supplemented with brief supportive sessions. This support could be delivered face-to-face, remotely, or in a group format.

The duration of guided self-help varies across programmes, although the NICE guideline gives the example of four to nine 20-minute guidance sessions over a period of 16 weeks. Weight loss is not an aim of treatment and treatments are likely to have a limited effect on body weight.

Group Cognitive Behavioural Therapy-ED (Group CBT-ED)

Group CBT-ED is recommended for children and young people diagnosed with binge eating disorder if guided self-help is unacceptable or ineffective. The treatment typically consists of 16 weekly 90-minute group sessions, and tends to include teaching the person about eating disorders, and supporting them to self-monitor their eating behaviours as a way to identify and overcome triggers to their binge eating. Weight loss is not an aim of treatment and treatments are likely to have a limited effect on body weight.

Evidence-Based Outpatient Treatments: Adults

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Summary:

- The type of treatment offered to your loved one will depend on things like their age and the sort of eating disorder they have.
- Their eating disorder service will use evidence-based guidelines when deciding which treatment to offer.
- This section describes the treatments your loved one is most likely to be offered.
- If you have any questions about your loved one's treatment, speak to their clinician or main support worker.

The type of treatment offered will depend on factors such as your loved one's age and diagnosis. The National Institute for Health and Care Excellence (NICE) guideline for eating disorders provides evidence-based recommendations for the treatment that your loved one should be offered. Based on this guideline, clinicians will start with the option that they believe will work best for an individual, but they may have to try more than one treatment before they find what best suits your loved one. If you have any questions about the treatment option your loved one has been offered, speaking to your loved one's clinician or main support worker is likely to resolve these.

The following pages are a list of NICE-recommended treatments. This list is comprehensive and may include elements that are not relevant to your loved one. Rather than feeling like you should read it all, focus on the treatment types that may be relevant for your loved one and read at your own pace.

Note that OSFED should be treated in the same way as the eating disorder it most closely resembles; therefore, there is no specific mention of OSFED. Additionally, the NICE guideline for eating disorders does not currently include recommended treatments for ARFID. This does not mean that it does not need specialist help and support. Due to the varied presentations that ARFID can take, your loved one can be treated by several different services and a range of professionals, including eating disorder services or general mental health professionals. Treatment should be tailored to the specific difficulties your loved one is having and the factors maintaining these.

Individual Eating-Disorder-Focused Cognitive Behavioural Therapy (CBT-ED)

CBT-ED is recommended for adults diagnosed with anorexia nervosa, bulimia nervosa or binge eating disorder. CBT-ED is also commonly used to support adults diagnosed with ARFID. In adults diagnosed with anorexia nervosa, CBT-ED tends to be considered as a first approach. In adults diagnosed with bulimia nervosa, CBT-ED is recommended if guided self-help is unacceptable or ineffective. In adults diagnosed with binge eating disorder, CBT-ED is recommended if guided self-help is unacceptable or ineffective, or if group CBT-ED is unavailable or declined. You may see the term "Enhanced Cognitive Behavioural Therapy (CBT-E)" being used – this is a variant of CBT-ED, and the NICE guideline does not distinguish between them.

CBT-ED is a talking therapy specifically for people diagnosed with an eating disorder, and is designed to be delivered on an individual basis. The idea behind to CBT-ED is that a person's thoughts, beliefs and behaviours interact, and so supporting the patient to change their disordered behaviours will result in changes to their thinking.

During CBT-ED, the clinician and patient work together to create a personalised treatment plan that addresses the factors maintaining the patient's eating disorder. Through treatment, strategies are put in place to help change the patient's disordered thoughts and behaviours. For example, the patient is asked to self-monitor what they eat and drink, and how this made them feel. This aims to help patients become more aware of what is happening in the moment, so that they can begin to challenge any disordered thoughts and make changes to behaviours that previously seemed out of their control.

- For patients diagnosed with anorexia nervosa, CBT-ED typically involves 40 sessions over 40 weeks.
- For patients diagnosed with bulimia nervosa, CBT-ED typically involves 20 sessions over 20 weeks.
- For patients diagnosed with binge eating disorder, CBT-ED typically involved 16 - 20 sessions.
- Typically, sessions are twice weekly for the first few weeks.

CBT and various counselling techniques helped unconsciously plant some tools to help me. Teaching myself to eat a healthy balanced diet and about proper nutrition was also helpful.

Guided Self-Help

Guided self-help is recommended as a first approach to treat bulimia nervosa and binge eating disorder in adults. It uses cognitive behavioural self-help materials designed specifically for eating disorders, and should be backed up by brief supportive sessions. This support could be delivered face-to-face, remotely, or in a group format.

The duration of guided self-help varies across programmes, although the NICE guideline gives the example of four to nine 20-minute guidance sessions over a period of 16 weeks. Guided self-help is likely to have a limited effect on the person's body weight, unless weight restoration is needed.

Group Cognitive Behavioural Therapy-ED (Group CBT-ED)

Group CBT-ED is recommended for adults diagnosed with binge eating disorder if guided self-help is unacceptable or ineffective after four weeks. The treatment typically consists of 16 weekly 90-minute group sessions, and tends to include teaching the person about eating disorders, and supporting them to self-monitor their eating behaviours as a way to identify and overcome binge eating triggers. Weight loss is not an aim of treatment and treatments are likely to have a limited effect on body weight.

Maudsley Anorexia Nervosa Treatment for Adults (MANTRA)

MANTRA is a treatment for adults diagnosed with anorexia nervosa. It begins by exploring the person's motivation to change, then helps the patient to understand how their illness developed and is being maintained. MANTRA helps the patients with areas such as nutrition and their thinking styles, as well as developing a new identity outside of the illness.

MANTRA consists of between 20 to 40 individual weekly sessions, dependent upon illness severity, as well as four or five follow-up meetings. Often family members or carers are involved to help the person understand their condition and change their behaviour.

Specialist Supportive Clinical Management (SSCM)

SSCM aims to help people recognise the link between their symptoms and their eating behaviours. Where necessary, it supports the person in returning to a healthy weight and developing healthy eating behaviours, through teaching them about the eating disorder and the impact it has on their life, as well as nutritional information and advice.

SSCM typically consists of 20 or more weekly sessions and is designed for adults with anorexia nervosa. Initially, specific symptoms of the illness are identified and goals for both weight restoration and normalised eating are decided upon. The specific symptoms are then monitored, and the patient is supported to achieve their treatment goals. The final phase consists of looking to future plans and discussing issues surrounding coming to the end of treatment.

Focal Psychodynamic Therapy (FPT)

Focal psychodynamic therapy is usually offered to adults if CBT-ED, MANTRA, and SSCM have been unsuccessful. The therapy aims to help the person understand how their eating habits and disordered behaviours are related to their thoughts, their self-esteem and their interpersonal relationships. FPT typically consists of up to 40 sessions over 40 weeks.

Summary:

- Most people with an eating disorder will be treated as an outpatient, which means they won't stay in hospital overnight.
- If there is a significant risk to someone's physical health, they may need to stay in hospital or be treated in a day patient service. Day patients tend to spend their weekdays in treatment but then go home in the evening.
- Once the person's physical health improves, they normally go back to having outpatient treatment.
- This section tells you about the different approaches to treatment, what happens if your loved one refuses to be treated, how you can make sure you are fully informed about your loved one's treatment and how to support it.

Inpatient and Day Patient Treatment

The NICE guideline recommends outpatient treatment for most patients with eating disorders. However, if an individual's physical health is severely affected, the guideline recommends that the patient is referred to either inpatient or day patient service to medically stabilise them and begin refeeding if needed. This can be necessary for any eating disorder and for both adults and children.

Day Treatment Programmes

Day treatment aims to medically stabilise the patient, normalise their eating and reduce disordered behaviours. Unlike inpatient treatment where patients remain in hospital during their admission, the patient returns home for evenings and most often weekends during day treatment. This allows patients to transfer the skills they learn to their home environment immediately. Day treatment programmes tend to involve the person attending the programme four or five days a week for a number of weeks, although the exact details will depend on the specific programme.

Inpatient Treatment

Inpatient programmes, where the patient remains at a treatment facility overnight as well as during the day, are utilised if the person's health cannot be safely managed in outpatient treatment or day treatment. They aim to keep the person safe and medically stabilise them. The NICE guideline for eating disorders recommends that inpatient treatment should be age-appropriate and near to the person's home. You should be kept involved with your loved one's care. After one month, your loved one's treatment should be reviewed to decide whether their inpatient admission should be continued, or treatment intensity stepped down.

Inpatient treatment can be a distressing time for both the person with an eating disorder and you as their carer. It takes time for everyone to adjust, and as a carer it can lead you to feel disempowered. Sometimes carers report feeling like it is a reflection of them or that it means they have failed as a carer – this is not the case and instead inpatient treatment is another way of providing additional support for your loved one.

Some carers also report feeling an element of relief if their loved one goes into an inpatient programme due to the impact the illness has had on themselves and others around them, yet then they feel guilty for thinking this way. Please remember that caring for a loved one with an eating disorder is extremely tiring and distressing. Having a loved one admitted to inpatient care can be an opportunity to recharge your energy levels, refresh your relationships and prepare to support your loved one when they come back home.

Medication

Medication should not be offered as the sole treatment for an eating disorder, as there are no medications that cure eating disorders. Some medications can help with common comorbidities of eating disorders, such as depression and anxiety, so it is worth consulting with your loved one's GP or psychiatrist about these.

The Mental Health Act and Compulsory Treatment

The NICE eating disorder guideline states: "if a person's physical health is at serious risk due to their eating disorder, they do not consent to treatment, and they can only be treated safely in an inpatient setting" then the Mental Health Act may be implemented. This can lead to the individual being detained, or "sectioned", so they can be treated. This can be very distressing for both yourself and your loved one, but is put in place to protect the patient's health or safety, or that of others.

If a child or young person's physical health is at serious risk, they are deemed to lack capacity, and they do not consent to treatment, then their parents or carers can be asked to consent on their behalf. If necessary, the appropriate legal action should then be followed.

More information on the Mental Health Act and legal frameworks can be found in the Resources section.

Transitions

Transitions between services, for reasons such as a change in location or moving to adult services from Child and Adolescent Mental Health Services (CAMHS), may make your loved one feel particularly vulnerable and you may want to make sure you're fully involved.

If your loved one is moving between services, you should receive full and timely information and good support surrounding the transition, and a care plan should be agreed by everyone involved, including the service that is taking over. For transitions between CAMHS and adult services, a key worker should be appointed to support both you and your loved one.

Transitions can be a difficult time for you as a carer. For example, when moving from CAMHS to adult services there is an increased onus on your loved one to take responsibility for their recovery. This can lead to carers feeling excluded and unsure of their role. If you are feeling this way, it could be helpful to speak to your loved one to ask how you can best support them. It could also help to speak to your loved one's clinician or main support worker to discuss how the transition will affect your role, including any differences in confidentiality, and how this can be managed. The NICE guideline states that carers should receive support and an assessment of their own needs, and this still stands even if your loved one is over the age of 18 years. Despite your role shifting, you can still play an important part in your loved one's recovery and provide invaluable support.

Challenging or Understanding Decisions Regarding Treatment

There may be times during your loved one's treatment when you are unhappy with decisions that have been made and wish to challenge your loved one's treatment team. In the first instance, it is worth either writing to the team to express your concerns – concise letters or emails will be more effective and get quicker replies. Template letters can be found on Beat's website (see the Resources section).

You may wish to try to arrange a face-to-face appointment with a specific member of the service to understand the decision that has been made, and, if necessary, to challenge this. Before this meeting it could help to write down a list of questions and things you wish to cover, to help you remain clear-headed during a potentially emotive meeting.

If you wish to take things further, the Patient Advice and Liaison Service (PALS) in England and Wales, and the Patient Advice and Support Service (PASS) in Scotland can help you to resolve problems when using the NHS. In Northern Ireland, the Patient and Client Council can help you to raise your concerns and resolve the situation. Contact details for these services can be found in the Resources section.

There are certain decisions that treatment teams do not have any control over such as commissioning decisions. For these, we suggest writing to the Chief Executive of the NHS Trust or Health Board, or to your local politician. More information on this can be found on Beat's webpage "Overturning bad decisions and understanding appropriate ones" (see the Resources section).

Finally, if these steps have not achieved the desired result, you can put in a formal complaint. The NHS complaints process varies across the UK, so the relevant websites for each country can be found in the Resources section.

What Increases the Risk of Developing and Maintaining an Eating Disorder?

Summary:

- **Anyone can get an eating disorder.**
- **Eating disorders develop due to a variety of different things. There is never a single cause.**
- **When someone has an eating disorder, this can affect how the brain works.**
- **These changes are normally reversible.**

Anyone can develop an eating disorder, regardless of age, gender, race, socioeconomic status, weight or background. There is no single cause of eating disorders. Although research is still evolving around why people develop eating disorders and how they are maintained, evidence suggests they are caused by a combination of biological, psychological, and sociocultural risk factors.

Examples of Biological Risk Factors:

- Genetics.
- Puberty/adolescence and changes that come with this.
- Abnormalities in the structure or activity of parts of the brain.

Examples of Psychological Risk Factors:

- Difficulties regulating emotions.
- Rigid thinking patterns.
- Low self-esteem.
- Over-evaluation of body image when defining self-worth.
- Trauma, including sexual, emotional or physical abuse.

Examples of Sociocultural Risk Factors:

- Internalisation of the 'thin ideal' portrayed by society.
- Body dissatisfaction.
- Prejudice towards people who are overweight or obese, or perceived to be so.
- Bullying (especially when directed towards weight or shape).
- Participation in certain activities that emphasise a specific body weight or shape e.g. ballet, gymnastics, athletics.

It is important to remember that people with the diagnosis of an eating disorder do not choose to have the illness and often are not in control of the behaviours that accompany the eating disorder. Recovery from an eating disorder is possible and there should always be hope. As a carer it can be very difficult to hold on to this hope and there will be days when the thought of your loved one recovering feels hard to believe. At Beat we hear from people every day who have made full recoveries from the eating disorder, and know that it is possible.

Eating Disorders and the Brain

Structural and functional differences in the brain are likely to develop due to malnutrition and also have a role in maintaining the illness.

This can result in reduced ability to think flexibly, regulate emotions, make decisions, or recognise, understand, or respond to how others are feeling. Additionally, an increase may be observed in compulsive and repetitive behaviours and emotional reactivity, for example.

Although this sounds scary, it's important to remember that the brain is constantly changing and adapting, and so most of the changes that are caused by the eating disorder are reversible. For example, studies have found that although the brain can shrink when someone is malnourished due to an eating disorder, there are no significant differences in brain volume in those who have recovered from the illness, compared to someone who has not had an eating disorder.

Glossary

This glossary is designed to help you learn more about some of the terms you may come across throughout this pack, and during your loved one's treatment.

Accommodating and enabling behaviours: Treatment may refer to 'accommodating and enabling behaviours'. These are things that carers may do to help reduce their loved one's distress, but that can result in the eating disorder dominating the house and routines, and becoming more entrenched. Examples of this may be cleaning up vomit or buying special foods.

AMHS: Adult Mental Health Services.

Binge: When the amount of food eaten is viewed as excessive and the person has felt a loss of control at the time of eating.

BMI (Body Mass Index): A statistical measure of height and weight.

CAMHS: Child and Adolescent Mental Health Services.

CPA (Care Programme Approach): A package of care that can be used to plan someone's mental health care, for example, their care co-ordinator and their treatment plan.

CEDS: Community Eating Disorder Service.

CBT (Cognitive Behavioural Therapy): Cognitive Behavioural Therapy is a talking therapy based on the idea that people's thoughts, feelings, and behaviours are all connected. It aims to help the patient manage their problems, through changing the way they think and behave. Enhanced Cognitive Behavioural Therapy (CBT-E) is a common variant of CBT, specifically designed to treat eating disorders.

CYP: Children and Young People.

Day treatment: The patient attends the specialist treatment programme more frequently than in traditional outpatient treatment (for example, four or five days a week), yet does not stay overnight.

DSM (Diagnostic and Statistical Manual of Mental Disorders): A manual used by clinicians and researchers to diagnose mental disorders. The latest version, DSM-5, was published in 2013.

ECG (Electrocardiograph): A test to measure the electrical activity of the heart.

EDNOS (Eating Disorder Not Otherwise Specified): A diagnostic term used in the fourth edition of the DSM (DSM-IV) to refer to eating disorders that did not fit all the symptoms of anorexia nervosa or bulimia nervosa.

FBT (Family-based treatment): FBT is a common variant of eating-disorder-focused family therapy.

Home treatment: The clinician provides treatment and support in the patient's home.

ICD (International Classification of Diseases): A classification and diagnostic tool, published by the World Health Organisation (WHO). The latest version is ICD-11.

Inpatient treatment: The patient stays overnight in a specialist hospital to help provide more intensive treatment and keep them safe.

Lapse: A temporary setback or slip. A lapse can be used as a learning point to help the person understand more about their triggers.

MARSIPAN: "Management of Really Sick Patients with Anorexia Nervosa". A resource designed to help clinicians and healthcare professionals manage the medical care of someone experiencing severe anorexia nervosa.

NICE (National Institute for Health and Care Excellence) guidelines: Evidence-based recommendations for health and care in England. They are normally also considered relevant in the rest of the UK.

Outpatient treatment: The patient is an outpatient so does not have to stay the night as part of their treatment (unlike in inpatient treatment).

%WFH (Percentage Weight for Height): A measure of children's body weight as a percentage of their ideal weight for their height, gender and age.

Purge: When the person tries to get rid of the food they have eaten, for example, through vomiting, taking laxatives or diuretics, excessive exercise or fasting.

Psychoeducation: An intervention where information is offered to the patient and their carers to help them learn more about the psychological disorder, for example, symptoms and treatment.

Refeeding syndrome: A rare but critical complication that can occur when someone who is malnourished begins to eat again. Blood tests can be used to check for this.

Relapse: The person slips back completely into their behaviours. Relapses can be used as learning points to help the person understand more about their triggers.

SSRIs (Selective Serotonin Reuptake Inhibitors): A widely used type of antidepressant.

Talking therapy: Therapies that involve talking to a trained professional about what is going on for the person and their difficulties.

Trigger: Something that results in the eating disorder thoughts and behaviours being more intense for the person.

Weight restoration: If someone is underweight, it is necessary for them to restore weight to become a healthy weight. The word "restore" is often preferable to the word "gain" when discussing weight, as can feel more contained and medically necessary, compared to "gaining", which is often equated to becoming fat.

Useful Resources

Who to Contact in a Crisis

The **Samaritans** are open 24 hours a day and can be called on 116123. They are a listening service who provide a safe space for you to talk at any time.

If you need medical care for yourself or your loved one urgently, then go to **Accident and Emergency**, or call **999.**

Websites Designed to Support Carers

Eating Disorders

Beat: beateatingdisorders.org.uk
Beat's website provides information about eating disorders and recovery, with resources for both you and your loved one. It also contains personal stories from those with lived experience.

Beat's support services:
beateatingdisorders.org.uk/support-services
Beat has multiple free and confidential support services, including a Helpline, open 365 days a year, and online moderated support groups.

Beat's family empowerment guidelines:
beateatingdisorders.org.uk/uploads/documents/2019/7/family-empowerment-guidance-1.pdf
Best practice guidelines for treatment providers around the engagement and empowerment of families and carers affected by eating disorders.

CaredScotland: caredscotland.co.uk
Provides information, through both text and videos, for parents and carers of young people who have recently received a diagnosis of an eating disorder.

Eva Musby: anorexiafamily.com
Provides practical and emotional support for parents supporting a child with an eating disorder, based upon Eva's own experiences of caring for a daughter with a diagnosis of anorexia nervosa. Eva's book, which provides practical support and advice for carers, can also be found on her website.

FEAST (Families Empowered and Supporting Treatment of Eating Disorders): feast-ed.org
Provides information about eating disorders and support, for example, through their online forum Around the Dinner Table:
aroundthedinnertable.org/

NICE Guideline: nice.org.uk/guidance/ng69
The NICE guideline provides evidence-based recommendations for the treatment that should be offered, and the support that should be offered to carers.

Siblings Support

Beat: beateatingdisorders.org.uk/uploads/documents/2017/10/young-carers.pdf
A resource designed to help under-18s caring for someone with an eating disorder.

CaredScotland: caredscotland.co.uk/entry-recovery/recovery-6
Provides hints and tips for supporting siblings.

NHS Lothian: caredscotland.co.uk/wp-content/uploads/2017/12/EDDT-Siblings-Self-Help-Pack.pdf
A self-help booklet for siblings of young people with experience of an eating disorder.

Carer Specific

Carers Direct: nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/helplines-and-forums
An NHS service for carers that provides information and support – includes a helpline that is open seven days a week.

Carers Trust: carers.org
Provides support to carers, including information about financial support and working rights.

Carers UK: carersuk.org
A charity supporting carers in the UK – includes an online forum to speak to other carers.

Legal Advice and Information about the Mental Health Act

Citizens Advice Bureau: citizensadvice.org.uk
Provides information about legal rights and responsibilities, including financial advice.

Rethink Mental Illness: rethink.org/advice-and-information/rights-restrictions/mental-health-laws/mental-health-act-1983
Provides information about the Mental Health Act.

Mind: mind.org.uk/information-support/helplines
A mental health charity that provides legal support through their website and their legal helpline.

NHS website: nhs.uk/conditions/eating-disorders
As well as providing information on eating disorders and their treatment, the NHS site also provides information on the Mental Health Act and related advice for carers.

Financial Support

Carer's Allowance: gov.uk/carers-allowance
Information about who is eligible for carer's allowance, and how to apply.

Disabled Students' Allowance: gov.uk/disabled-students-allowances-dsas
Information about who is eligible for DSA, and how to apply.

Challenging and Understanding Decisions

Beat: beateatingdisorders.org.uk/support-services/overturning-bad-decisions
A webpage designed to help people to overturn bad decisions and understand appropriate decisions around treatment. Page includes template letters and emails.

Patient Advice and Liaison Service (PALS): nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service
Offers advice and support on health-related matters, including problems with the NHS in England. Includes information on how to make a complaint to NHS England or the local clinical commissioning group.
Making a complaint: england.nhs.uk/contact-us/complaint

Patient Advice and Support Service (PASS): cas.org.uk/pass
Provides practical and emotional support to help people manage problems with the NHS in Scotland.
Making a complaint: mygov.scot/nhs-complaints

Health in Wales: wales.nhs.uk/ourservices/directory
Provides a directory of Health Boards in order to direct people to the area-specific procedure for making a complaint in Wales.
Making a complaint: wales.nhs.uk/ourservices/contactus/nhscomplaints

Patient and Client Council: patientclientcouncil.hscni.net
Provides support and information about health and social care problems, including how to make a complaint in Northern Ireland.
Making a complaint: nidirect.gov.uk/articles/make-complaint-against-health-service

General Mental Health Support

Mind: mind.org.uk
A mental health charity that provides information and support.

Rethink Mental Illness: rethink.org
Provides advice and support on topics related to mental illnesses.

Self-Compassion

Compassionate Mind: compassionatemind.co.uk/resources/exercises
Provides information and exercises to help someone engage in self-compassion.

Compassionate Mind Sound Cloud: soundcloud.com/compassionatemind
Provides exercises to help someone engage in self-compassion.

Internet Safety

NSPCC: nspcc.org.uk/preventing-abuse/keeping-children-safe/online-safety
Provides information about keeping children safe online.

Web page addresses change from time to time. If the link printed here is broken, please check Beat's website for the updated address.

Books

Carer Skills

Skills-based Learning for Caring for a Loved One with an Eating Disorder: The New Maudsley Method by Janet Treasure, Gráinne Smith and Anna Crane
Provides skills and knowledge for carers, guiding a carer to be like a "dolphin", swimming alongside their loved one and gently encouraging them.

Help Your Teenager Beat an Eating Disorder, Second Edition by James Lock and Daniel Le Grange
Presents evidence that parents often play a key role in their child's recovery, and offers practical advice and support.

When Your Teen Has an Eating Disorder: Practical Strategies to Help Your Teen Recover from Anorexia, Bulimia, and Binge Eating by Lauren Muhlheim
Provides practical advice and strategies to empower carers to help support their teenager's recovery.

ED Says U Said: Eating Disorder Translator by June Alexander and Care Sangster
Describes the internal dialogue that people diagnosed with eating disorders often experience, and provides suggestions for how someone with an eating disorder may interpret different phrases or situations.

Cognitive Behavioural Therapy Specific

Beating Your Eating Disorder: A Cognitive Behavioural Self-Help Guide for Adult Sufferers and their Carers by Glen Waller, Victoria Mountford, Rachel Lawson, Emma Gray, Helen Cordery and Hendrik Hinrichsen
A self-help guide to help adults diagnosed with anorexia nervosa and bulimia nervosa in their recovery, and to teach skills to carers based upon cognitive behavioural therapy.

Family Specific

Anorexia and other Eating Disorders: how to help your child eat well and be well: Practical solutions, compassionate communication tools and emotional support for parents of children and teenagers by Eva Musby
Written by the mum of someone with anorexia nervosa. Offers a wealth of knowledge, including practical advice for managing mealtimes, information about helpful and unhelpful things to say, and advice on developing emotional resources as a carer.

Survive FBT: Skills Manual for Parents Undertaking Family Based Treatment (FBT) for Child and Adolescent Anorexia Nervosa by Maria Ganci
Provides practical advice to empower parents undertaking Family Based Treatment with their child.

Anorexia Nervosa Specific

Decoding Anorexia by Carrie Arnold
Explains anorexia nervosa from a biological but user-friendly perspective – this can be helpful for carers who wish to know more about the science behind their loved one's behaviours. These scientific descriptions are paired with personal narratives and examples.

ARFID Specific

Food Refusal and Avoidant Eating in Children, including those with Autism Spectrum Conditions: A Practical Guide for Parents and Professionals by Gillian Harris and Elizabeth Shea
Provides support and understanding around avoidant/restrictive food intake disorder (ARFID).

ARFID Avoidant Restrictive Food Intake Disorder: A Guide for Parents and Carers by Rachel Bryant-Waugh
Provides practical tips and strategies to help equip carers of someone with a diagnosis of ARFID.

Binge Eating Disorder Specific

Overcoming Binge Eating, Second Edition: The Proven Program to Learn Why You Binge and How You Can Stop by Christopher Fairburn
Presents information about eating disorders followed by an evidence-based self-help programme for overcoming binge eating problems. Carers often find the information section a useful resource for aiding their understanding of eating disorders.

Peer-to-Peer Support

Beat's peer support for carers: beateatingdisorders.org.uk/supporting-someone/services-carers
Beat offers a range of peer support for carers, including online groups and one-to-one telephone support.

Beat's HelpFinder database: helpfinder.beateatingdisorders.org.uk
Lists locally-run face-to-face support groups.

F.E.A.S.T (Families Empowered and Supporting Treatment of Eating Disorders): feast-ed.org
Provides information and online support. This includes a specific peer-to-peer support forum, aroundthedinnertable.org

Skills Training for Carers

Developing Dolphins: beateatingdisorders.org.uk/training-cpd/developing-dolphins
Beat's two-day workshop to help carers understand their loved one's illness and help ensure that they are able to support their treatment and recovery.

Coping with Christmas: beateatingdisorders.org.uk/training-cpd/coping-with-christmas
Beat's one-day workshop to help people caring for someone with an eating disorder cope with the particular challenges that come with Christmas.

Beat's suite of training and support services for carers is being expanded. Please check beateatingdisorders.org.uk/training-cpd for updates.

Veronica Kamerling's co-dependency workshops: eatingdisordersandcarers.co.uk/training
Helps carers who are struggling with co-dependency.

Web page addresses change from time to time. If the link printed here is broken, please check Beat's website for the updated address.